Building a Collaborative Biomedical Network

Question and Answer Session from the caBIG® 2010 Annual Meeting
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So before I start with our prestigious speakers, I wanted to take a few minutes to update you all on some of the activities that we're doing in caBIG® around creating an electronic health environment that brings together both the provider framework, electronic health records, that will support the delivery of care as well as beginning the process of empowering consumers to both have access to that electronic health information as well as bring in their own unique experiences to the cancer endeavor.

These efforts are being done under the framework of two different efforts, one directed at providers, the other directed at consumers. But as you're aware from our caBIG® models, the idea is to blend and connect this information in unique and novel ways. So I'll start with showing a portal, a prototype that we're creating that we hope to be sharing in partnership with professional organizations and other groups to give access to providers to electronic infrastructure to support their care delivery. Shown here is a prototype of what this portal would look like. It allows the provider to be able to log in and be able to begin to manage their information on their cancer care electronically by creating, in this instance, ultra light electronic health records, leveraging the technology and frameworks that we've heard before. And this is a working prototype that we've established today that allows a straightforward simple summary of patient care that can be used by providers to track their patients, as well as then be used to bring together the information using a common set of analytics that would allow them to see the trends in the patients that they've been working with, the patterns of disease they've been seeing, as well and perhaps more importantly map this onto the outcomes that have been associated with their treatments.

But as you guys are aware and from my opening comments, the focus on providers, while important, is only one half of the puzzle. There are critically other insights that are essential if we're going to balance the care delivery spectrum. So we've also been working and attempting to recruit advocacy communities to be facilitating the systematic capture and empowerment of patients to have access to this type of structured electronic information. Shown here an example mock up portal that an advocacy group could leverage under the title of My Cancer e-LIFE, and you can see we've been talking to a number of individual advocacy groups that might want to be branding such portals.

Through these portals, patients then would be able to take control of their health information as well as have a place that they can actively seek information to manage their health as well as their disease. So through this they would be able to request access. As you all are probably aware through high tech and the health reform

activities, it's now a requirement that physicians be able to provide electronic copies of health records to requesting patients. And in this instance, we create a framework by which that information can be requested. You can see here that this can handshake with the previous provider resource I showed a moment ago and then bring in this particular care summary record that could be generated either from the provider perspective or from any other electronic health infrastructure that a provider may be using.

So through this then, the patient now has and can maintain and use this record however they may see fit. But it also allows them to track other pieces of information that aren't part of the traditional health infrastructure, for instance, a whole variety of things related to their health and to the management of their disease. And through this type of work, they can track information on their health, information on their sleep patterns, information on their pain and bring all this information together in a standardized journal and track it over time so that we round out the information available to individuals in this context and not just have the information that would be trapped in a traditional provider-based electronic health record.

So through this information, once it's present in this electronic form, it can be used to help people find additional information, guide them to different places of resources that—whether they be NCI or ACS or other groups of information, would allow them to be able to direct news feeds so that they could stay on top of what's breaking in terms of their particular areas of health concern and, again, driven by the structured information in their record. It would allow them to seek out actively clinical trials for participation and allow them to look for, either from NCI resources or other resources, the way to actually be part of specific clinical trials.

But perhaps most importantly it would allow them, because they now control their records, to share this information both with other patients in a de-identified, aggregated form or into resources that would be available for further research or for further participation in other types of investigations. So through this they would be able to have access to aggregated, de-identified information that would allow them to see their experience in the context of others, as well as provide this information then back to their physician so that the physician now has a more rounded view of what's actually happening, not just what was in the particular encountered but other variables and, again, now going back to matching profiles in a conversation with their physician could then now not only see the information that was present in their traditional medical record, but now can have projected on to that information that was important to the patient as well. So shown here now seeing the outcomes integrated with information, say, for instance, on degree of pain or change in mood or average quality of sleep and seeing how these individual variables then would be interacting and a structured conversation can then occur between patient and physician where both are now partners and both people's information is electronically available.

Speakers:

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